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**Health and Mortality Risks for Caregivers Vary by Age: A Census-Based Record
Linkage Study.**

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Running head: Young Caregivers Differ from Older Caregivers

Abstract

Due to the focus of studies about caregiving responsibilities on older caregivers, there has been a deficit of research on young caregivers. We aimed to investigate the association between caregiving and health/ mortality risk in young caregivers when compared with their non-caregiving peers and older caregivers. A census-based record linkage was implemented linking all residents enumerated in the 2011 Northern Ireland Census with subsequently registered deaths data, until the end of 2015. Among those aged 5-24 years at the 2011 Census, approximately 4.5% (19,621) of the cohort reported that they were caregivers. The presence of a chronic physical (mobility difficulties) and/or mental health condition was measured through the Census; all-cause mortality was assessed by official mortality records. Young caregivers were less likely than their non-caregiving peers to report chronic mobility problems (OR_{adj} 0.81 95%CI 0.84, 0.96), but more likely to report chronic poor mental health (OR_{adj} 1.44 95%CI 1.31, 1.58). They also differ from older caregivers ($P < 0.001$) and are at significantly higher mortality risk than their peers (HR_{adj} 1.54 95%CI 1.10, 2.14). A dose response relationship between hours devoted to caregiving duties and mortality risk was evident. Young caregivers are at significantly increased risk of poor health outcomes.

Keywords: mental health, mortality, young caregivers, record linkage

An ageing population, aligned with an increasingly strained formal sector, places ever growing reliance on the large body of unpaid informal caregivers who provide support and assistance for families, friends and neighbours. The health and well-being of caregivers is therefore of concern and as the proportion of the population engaged with caregiving increases with age (1) most research in this area relates to older caregivers. While the majority of studies find that caregiving may be associated with poor mental and emotional health (2-5), this has been moderated by growing recognition that caregivers as a group have reduced mortality risk compared to non-caregiver peers (6-13). Recent overviews (14,15) have argued for a more balanced and positive perspective on caregiving.

However, few studies have examined the health of young caregivers and none we are aware of have examined their mortality risk. Yet this is an important group of possibly vulnerable caregivers who have been described as invisible or hidden (16,17). According to the 2011 Census there were 177,918 young unpaid caregivers (aged 5-17) in England and Wales, an increase of 19% on 2001 Census estimates (18). Approximately 80% were providing fewer than 20 hours of unpaid care per week, with 9% providing ≥ 50 hours. For the UK Census, young caregivers were defined as *“people ≤ 18 -years-old (aged 5-17), providing unpaid care for family members, friends, neighbours or others because of long-term physical or mental ill-health, disability, or problems relating to old age”*. A cross-sectional analysis of the 2001 UK Census data showed that caregivers aged 5-15 reported poorer self-rated general health than non-caregiving peers (19), an association confirmed by the 2011 Census (18), highlighting the need to focus on the potential impact of caregiving on the health and life-chances on the young caregivers.

There are a number of reasons why caregiving may be deleterious to the health and well-being of young caregivers. Providing care can interfere with school work and the formation of healthy social networks, thereby creating issues with other aspects of social and emotional

development and leading to a problematic transition to adulthood (20,21). A lack of social interaction might stem from the inability to incorporate such activities in their restrictive caregiving routine, making it less likely for their needs to become visible and be addressed (22). This may add to the pre-existing burden on young caregivers who are more likely to come from single parent or low income families (20,23-25). Thus, there is reason to believe that many of the positives associated with caregiving at older ages may not hold true for younger ages, with children/adolescents being more vulnerable than young adults, when exposed to age-inappropriate responsibilities before developing strong supportive networks during early life.

Previous studies of the mental health of caregivers have limitations, including inconsistent definition of the burden of care on the caregiver (26), small homogeneous diagnostic samples that are not representative of the population as a whole (27), lack of comparison groups (28) and insufficient adjustment for confounding factors (29). Many of these studies were based on contact with specific initiatives such as the Young Carer Projects and may be biased as they may not include hard-to-reach groups or those caregivers with no problems that would bring them into contact with such organisations, therefore raising concerns about representativeness (30,31). Furthermore, assessment of early caregiving experiences through recall may cause problems in the interpretation of previous findings as it may lead to reporting of false memories that vary according to age (32).

The aims of this study are (i) to compare the physical and mental health of young caregivers and non-caregiving peers (ii) to measure the mortality experience of young caregivers and (iii) to compare the health and mortality experience of young and older caregivers.

METHODS

This was a 2011 Census-based mortality linkage study. It utilized data from the Northern Ireland Mortality Study, a population-wide study linking Census returns for all enumerated individuals to mortality records from the General Register Office. A full description of the cohort and the linkage procedures is available elsewhere (8). For this study, data on all residents enumerated in the 2011 Census were linked to death records registered until the end of 2015 (a follow-up period of 57 months). The linked data were anonymised, held in a safe setting by the Northern Ireland Statistics and Research Agency and made available to the research team for the purpose of this study. The use of the Northern Ireland Mortality Study for research was approved by the Office for Research Ethics Committees Northern Ireland.

Cohort description

The cohort for analysis included all individuals enumerated in the 2011 Census, aged ≥ 5 and not residing in institutional care. However, as most previous studies concerned older caregivers, the main focus here is on those aged 5-24, with most of the analyses performed separately for children and adolescents (aged 5-17) and young adults (18-24), as people ≤ 18 have been previously considered a distinct group (18) and it was anticipated that adverse caregiving effects could be more pronounced at these ages due to greater encroachment on education and social developments. All cohort attributes were derived from the 2011 Census records. The Census form indicates the householder (the person who owns or rents the accommodation and is responsible for paying the household bills) as responsible for “*ensuring that the questionnaire is completed and returned*”; the form does not give instructions as to who should complete individual parts of the Census form. However, it is generally anticipated that parents would complete the individual forms on behalf of younger children while older children may complete on their own behalf. Individual characteristics included gender and age, and because Northern

Ireland is an ethnically homogenous country ethnic diversity was summarised as white/non-white. Households were classified as single parent, or not, according to the number of parents residing in the household. Socio-economic status was assessed using household car availability (\geq two, one car, none) and housing tenure (grouped as owner occupier, private renter and social renter). An indication of locale was included (33): grouped as urban (settlements of $>75,000$ people), intermediate (2,500-75,000) and rural ($<2,500$).

Caregiving status

Caregiving was defined according to the 2011 Census question: *“Do you look after, or give any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill-health/disability; problems related to old age?”* with response categories - non-caregiver, caregiving for 1-19hours, 20-49, and ≥ 50 hours-per-week. Respondents were instructed not to include anything they did as part of paid employment. There were no questions related to either the care-recipient or the nature of the caregiving duties. For this study, we derived two indicators summarising caregiving activity: a binary (non-caregiver; caregiver) and a three-category version (non-caregiver; caregiving for 1-19hours; or ≥ 20 hours-per-week). This division has been adopted elsewhere with ≥ 20 hours-per-week representing more intense caregiving (34,35).

Health and mental health status

Physical and mental health was assessed using two questions: (i) the presence of health problems or disability that limit day-to-day activities either *“a little”* or *“a lot”*, and persisting or expected to persist for a minimum of 12 months; and (ii) asking about the presence of specific chronic conditions: *“Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?”* – with respondents ticking all that

apply from a list of stated conditions. Cohort members were deemed to have chronic mobility problems if they reported: “*a mobility or dexterity difficulty (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs lifting or carrying)*”; and chronic poor mental health if reporting: “*an emotional, psychological or mental health condition (such as depression or schizophrenia)*”. The strengths and caveats of this binary mental health measure are further discussed elsewhere (36).

Mortality risk

All-cause mortality was assessed by including all recorded deaths from the General Registers Office from the Census until December 2015.

Analysis

All analyses were carried out using STATA 14 (Stata Corp LP, College Station, Texas). The cohort comprised 1,744,681 people aged ≥ 5 at the Census of whom 433,328 were aged 5-24. Descriptive statistics recorded the socio-demographic characteristics and variations in baseline health status by caregiving activity for young caregivers and logistic regression to determine the factors related to being a caregiver.

The relationship between caregiving and physical and mental health amongst young caregivers was explored using logistic regression with separate models for 5-17 and 18-24-year-olds. Models examining mental health also included adjustment for variation in physical health in addition to the other demographic and socio-economic factors. Absolute differences in mortality risk by caregiving were estimated using standardised death rates and relative risks using Cox Proportional Hazards models; adjusting for all baseline measures of mental and physical health status. Because of the relative rarity of deaths at younger ages, mortality risk was calculated only for the combined 5-24 age-group.

Finally, tests for interaction were carried out to determine if the relationship between caregiving and health or mortality risk varied by age, with separate stratified analyses run for positive interactions.

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RESULTS

Approximately 4.5% (19,621) of the 5-24-year-old cohort reported that they provided informal care (see Web Figure 1 for proportion of caregivers across all age-groups). Table 1 shows the baseline characteristics of the young cohort by caregiving status and the results of logistic regression models with caregiver as the dependent variable (see Web Table 1 for a 5-17 & 18-24 years split). Although there were nearly twice as many children and adolescents than young adults in the cohort, young adults (18-24) were more likely to be caregivers (OR3.10 95%CI3.01,3.19). Caregiving was more common amongst women and less common amongst non-white ethnic minorities. Although almost twice as many young caregivers lived in households with ≥ 2 parents, the risk of being a caregiver was increased for those living in single parent households (OR1.31, 95%CI1.27,1.36). The odds of being a young caregiver were higher for those living in social rented accommodation rather than in owner occupation (OR1.23 95%CI1.17,1.29), and those in households with no car access were less likely to be caregivers (OR0.86 95%CI0.82,0.91). In terms of health, caregiving was more likely amongst those with some limitation of daily activity, but less likely for those with severe limitation (OR1.44 95%CI1.35,1.55 and OR0.60 95%CI0.54,0.68 respectively). Compared to non-caregiving peers, young caregivers were less likely to report chronic mobility difficulties (OR0.84 95%CI0.73,0.96), but more likely to report chronic poor mental health (OR1.44 95%CI1.31,1.58).

Insert Table 1

Chronic mobility problems

Table 2 shows the odds of reporting chronic mobility problems amongst young caregivers by intensity of caregiving. While tests for interactions showed this didn't vary by age ($P=0.314$), the analysis was stratified for children/adolescents and young adults to maintain consistency

with the remaining analyses. Caregiving was more common amongst young adults (7.9% vs 2.7%), with a higher proportion undertaking more intense caregiving. In both age-groups less intensive caregiving was associated with a 35-40% reduced odds of reporting chronic mobility problems but, while young adults were less likely than non-caregiving peers to report mobility problems (OR0.86 95%CI0.69,1.08), those aged 5-17 were more likely (OR1.61 95%CI1.16,2.23).

Insert Table 2

Chronic mental health problems

Table 3 shows the equivalent results for reporting chronic mental health problems, again stratified by age as tests for interaction showed that mental health varied between 5-17 and 18-24year-olds ($P=0.022$). In both age-groups caregiving was associated with increased odds of reporting chronic mental health problems though this was more marked for children/adolescents and young adults where a dose-response relationship was evident. Within this age-group, those providing more intensive caregiving were more than twice as likely as non-caregiving peers to have poor mental health (OR_{adj}2.46 95%CI1.70,3.56). The prevalence of chronic poor mental health was about 30% higher amongst young adult caregivers though with no difference by caregiving intensity.

Insert Table 3

Mortality risk

There were 477 deaths to the cohort members aged 5-24 (from 63,308 recorded over all age-groups), of whom 7% were to caregivers. In contrast to the analysis of mobility and mental health difficulties, which split young caregivers into two age-groups, the analysis of mortality does not subdivide the cohort because of low numbers of mortality events in those aged 5-24. The mortality risk for young caregivers after adjustment for age, sex and marital status was HR1.40 95%CI1.01,1.95 compared to non-caregiving peers, though this excess increased

(HR_{adj}1.54 95%CI1.10,2.14) on full adjustment for a range of factors, including activity limitation and mental ill-health (Table 4). A dose-response between caregiving intensity and mortality risk was also evident with adjusted hazard ratios of 1.21 (95%CI0.70,1.89) for light caregivers and 2.16 (95%CI1.36,3.43) for those providing ≥ 20 hours of caregiving per-week; with standardised death rates showing a similar picture.

Insert Table 4

Older and young caregivers

Finally, Figures 1, 2 and 3 show the variation in the relationship between caregiving, health status and mortality risk across the age-range. Interaction tests showed these varied by age ($P=0.020$ and $P<0.001$ respectively). While there was no such variation in the odds of reporting chronic mobility problems ($P=0.230$) it is included for completeness. The figures show the results of separate logistic regression or Cox proportional hazards models, fully adjusted for the covariates discussed above, with non-caregiver as the reference category. The models were stratified by age-group: 5-17, 18-24, 25-44, 45-64 and ≥ 65 years in the logistic regression; while for the mortality analysis the two youngest age-groups were combined.

At all ages, those providing lighter caregiving reported fewer chronic mobility problems while more intense caregiving was mostly indistinguishable from those of non-caregivers, the one exception being the higher levels amongst the youngest caregivers.

Insert Figure 1

In contrast, the odds of reporting poor mental health were inversely related to age. At older ages, less intense caregiving is associated with a reduced risk of chronic poor mental health but by age 25-44 this has reversed and caregiving is associated with increased risk. The highest risk of poor mental health is at the youngest ages.

Insert Figure 2

With mortality, the pattern is similar to that for mental health problems: by age 25-44 the lower mortality risk evident at older ages for both categories of caregiving had disappeared and at lowest ages more intensive caregiving was associated with an increased risk.

Insert Figure 3

ORIGINAL UNEDITED MANUSCRIPT

DISCUSSION

Principal findings

This is the first population-wide study focusing specifically on the health, mental health and mortality risks associated with caregiving among young people, a group usually missed from the literature. It demonstrates that, although young caregivers generally present with better physical health than non-caregiving peers, they are more likely to report chronic poor mental health and are at significantly increased mortality risk.

Comparison with other studies

The study confirms the socio-economic characteristics of young people found in other studies (20,23-25). It also confirms their better functioning and worse mental health, while overcoming some of the limitations relating to the methodology of earlier studies (28,30). The reduced risk of such chronic mobility difficulties for those aged 18-24 accords with earlier studies indicating that caregivers might present with better functioning than non-caregiver peers (37) - however, this protective effect could be due either to the physical requirements of the caregiving role or an instance of “selection into the role” by healthier individuals. The dose-response patterns concerning mental ill-health are also consistent with previous studies indicating that the odds of experiencing psychological distress are elevated among individuals providing care for ≥ 20 hours-per-week, due to the intensity and duration of the caregiving activities (2).

While the lower mortality of older caregivers recorded in previous studies (6-13) is confirmed, the increased mortality associated with young caregivers has not previously been reported. We believe that this a real phenomenon based on the following key points: the significant interaction term shows that the relationship between caregiving and mortality is

modified by age, and this is demonstrated graphically; the relationship between caregiving and mortality is substantial and persists despite robust controls for baseline health and other potential socio-demographic confounders; a strong dose-response relationship between caregiving intensity and mortality observed among young caregivers; and finally, while the findings are most pronounced at the youngest ages, they form part of a continuum from older ages. This suggests that caregiving responsibilities might have a very different effect on the individual across the age-spectrum.

At older ages, where activities such as paid employment no longer apply and individuals are more likely to act as sole caregivers, caregiving may provide a purposeful role that tightens interpersonal bonds commensurate with expectations of both age and extant relationships (6), caregiving being seen as a potential but natural progression and positive caregiving attributes being associated with lower mortality risk in older people (6-7,15,37-39). At younger ages, the expectations of role relationships and function are different and significant caregiving responsibilities are likely to be at variance with perceived social norms. In contrast to older ages, young caregivers may feel constrained in undertaking a role they had little choice in accepting and consider inappropriate for their age (20). The feeling of duty to provide care, either normatively or due to the lack of alternatives, has been linked to higher caregiving burden and worse outcomes among child caregivers (40). Pressures arising from caregiving duties and associated time commitments may result in competing demands and curtail the opportunities for “normal” social interaction and social development leading to what has been called a ‘lost or stolen childhood’ (41). It is well established that care-provision among young people is often associated with lower levels of educational attainment and subsequent reduced potential for employment (20). The disruption of usual social life and social networks (31,42), which in normal circumstances would act to mitigate the overall caregiving burden

through sharing responsibilities with family or friends, could further increase the deleterious effects of caregiving for young people.

Study strengths and limitations

This study has a number of methodological strengths and limitations that should be mentioned. While the Census has unsurpassed population coverage and encompasses many 'hard to reach' groups, it may miss out a disproportionate proportion of non-enumerated young adults and caregivers in deprived inner city areas (43), though this is unlikely to have significantly biased the associated morbidity or mortality risks. The proxy nature of Census returns, while a concern in considering young people, is less of a problem at older ages where most ill-health and mortality occurs. It is likely that a parent or guardian rather than the younger person completes the 'self-assessed' health question, which might lead to confounding for these measures, though not for mortality risk which is the primary focus of the study. Additional limitations relate to the absence of information about the duration or nature of caregiving and the inability to explore this in relation to the level of disability or the type of relationship to the person towards whom it is directed. As this is an observational study the possibility for uncontrolled confounding, such as care-related stress, or a reverse association between caregiving and health outcomes cannot be entirely discounted. Furthermore, as others have suggested (15,44), having a close family member with serious disability can also lead to stress or mental ill-health regardless of whether one is providing care.

In previous studies where a mortality advantage of caregiving amongst older people was evident, potential health selection effects (i.e. those taking up a caregiving role are intrinsically healthier (37,45)) was always a concern. However, this cannot explain the higher

mortality of young caregivers and the relatively small change in the hazards after adjustment for socio-economic status at baseline, suggesting that the reduced mortality risk is not due to residual differences in deprivation.

Implications

The number of young caregivers is increasing (1,18) and is likely to increase further partly as a consequence of the trend towards later parenthood (30), but mostly because financial pressures on formal care-services will place a greater reliance on the informal caregiving sector. While recognising which individuals are most at risk is crucial to ensure those most in need receive support, we recognise that this is difficult. Studies have consistently shown that only a small proportion of young caregivers are identified by official services and this may be because of a combination of factors including lack of awareness amongst professionals, a lack of awareness amongst young caregivers of their entitlements or a reluctance to engage with health and social services for fear that families could be broken up and children taken into care (16,40,46). More needs to be done to increase awareness among professional groups of the needs and concerns of young caregivers, perhaps by involving care-recipients, who might also be family members, during contact with healthcare services. There is an increasing need for these services to focus on family units rather than solely on the disabled person or patient. The new UK Care Act implemented in 2016 is aimed at assessing the needs of care-providers and enhancing connection to services providing support. It is also recognised that young caregivers value opportunities to talk to someone who will listen sensitively and respectfully, and believe the descriptions of their circumstances (16). The voluntary sector and charities such as Carers UK also have an important role in bringing the voices and choices of young people to wider fora.

Conclusion

This study provides stark evidence of the significant negative impact that caregiving can have on younger people. It is important that more is done by formal services to recognise and address the needs of these vulnerable young people who are all too often hidden from official observation.

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Table 1.

Characteristics of Caregivers Aged 5-24 Years at the Time of the 2011 Northern Ireland Census. N=433,328

Population Characteristics	Non-caregiver		Caregiver		Adjusted for age/sex ^a		Fully adjusted ^a	
	N	%	N	%	OR	95CI	OR	95CI
Age								
5-17	273,538	97.3	7,623	2.7	1.00		1.00	
18-24	140,169	92.1	11,998	7.9	3.07	2.98-3.16	3.10	3.01-3.19
Sex								
Male	211,898	96.1	8,675	3.9	1.00		1.00	
Female	201,809	94.9	10,946	5.1	1.32	1.28-1.35	1.31	1.28-1.35
Ethnicity								
White	405,574	95.5	19,350	4.5	1.00		1.00	
Non-white	8,133	96.8	271	3.2	0.77	0.68-0.87	0.81	0.72-0.92
Single parent household								
No	302,167	95.8	13,270	4.2	1.00		1.00	
Yes	111,540	94.6	6,351	5.4	1.32	1.28-1.36	1.31	1.27-1.36
Housing								
Owner	289,977	95.7	13,041	4.3	1.00		1.00	
Social renting	69,804	95.5	3,281	5.7	1.30	1.25-1.35	1.23	1.17-1.29
Private renting	53,926	94.3	3,299	4.5	0.89	0.85-0.92	0.88	0.85-0.92
Car availability								
≥2	223,244	95.6	10,295	4.4	1.00		1.00	
1	130,600	95.5	6,209	4.5	1.11	1.08-1.15	1.02	0.99-1.06
0	59,863	95.1	3,117	4.9	1.04	1.00-1.09	0.86	0.82-0.91
Area of residence								
Urban	155,101	95.1	8,056	4.9	1.00		1.00	
Intermediate	137,692	95.9	5,964	4.2	0.87	0.84-0.90	0.89	0.86-0.92
Rural	120,914	95.6	5,601	4.4	0.97	0.94-1.01	1.02	0.98-1.05
Activity limitation								
None	386,623	95.5	18,147	4.5	1.00		1.00	
Little	15,210	93.3	1,097	6.7	1.54	1.45-1.64	1.44	1.35-1.55
Lot	11,874	96.9	377	3.1	0.66	0.60-0.73	0.60	0.54-0.68
Mobility difficulties								
No	407,006	98.4	6,701	1.6	1.00		1.00	
Yes	19,436	98.6	275	1.4	0.78	0.69-0.89	0.84	0.73-0.96
Mental health								
No	407,221	95.5	18,997	4.5	1.00		1.00	
Yes	6,486	91.2	624	8.8	1.39	1.28-1.52	1.44	1.31-1.58

N: number of people; %: percentages; OR: odds ratios; CI: confidence intervals
a. odds ratios from logistic regression models

Table 2.

Caregiving Status and Odds Ratios for Reporting Chronic Mobility Difficulties at the Time of the 2011 Northern Ireland Census, Estimated Using Logistic Regression Models Stratified by Age of Caregiver.

Caregiving status & Caregiver Age	Study Participants		Mobility Difficulties		Model 1 ^a		Model 2 ^b		Model 3 ^c	
	No.	%	No.	%	OR	95CI	OR	95CI	OR	95CI
Aged 5-17										
Non-caregiver	273,538	97.3	3,842	1.4	1.00	Referent	1.00	Referent	1.00	Referent
Care 1-19 hours/week	6,096	2.2	52	0.9	0.61	0.47, 0.81	0.61	0.47, 0.81	0.62	0.47, 0.82
Care ≥20 hours/week	1,527	0.5	38	2.5	1.81	1.31, 2.50	1.67	1.20, 2.32	1.61	1.16-,2.23
Aged 18-24										
Non-caregiver	140,169	92.1	2,869	2.0	1.00	Referent	1.00	Referent	1.00	Referent
Care 1-19 hours/week	8,097	5.3	106	1.3	0.64	0.52, 0.77	0.64	0.52, 0.77	0.64	0.52, 0.78
Care ≥20 hours/week	3,901	2.6	79	2.0	1.00	0.80, 1.26	0.86	0.69, 1.08	0.86	0.69, 1.08

No.: number of people; %: percentages; OR: odds ratios from logistic regression models; CI: confidence intervals

a: adjusted for age, sex and marital status

b: Model 1+ SES

c: Model 2 + area of residence

Table 3.

Caregiving Status and Odds Ratios for Reporting Poor Mental Health at the Time of the 2011 Northern Ireland Census, Estimated Using Logistic Regression Models Stratified by Age of Caregiver.

Caregiving status & Caregiver Age	Study Participants		Poor Mental Health		Model 1 ^a		Model 2 ^b		Model 3 ^c	
	No.	%	No.	%	OR	95CI	OR	95CI	OR	95CI
Aged 5-17										
Non-caregiver	273,538	97.3	1,883	0.7	1.00	Referent	1.00	Referent	1.00	Referent
Care 1-19 hours/week	6,096	2.2	62	1.0	1.52	1.18, 1.96	1.58	1.23, 2.05	1.98	1.51, 2.59
Care ≥20 hours/week	1,527	0.5	35	2.3	3.38	2.40, 4.75	2.77	1.97, 3.90	2.46	1.70, 3.56
Aged 18-24										
Non-caregiver	140,169	92.2	4,603	3.3	1.00	Referent	1.00	Referent	1.00	Referent
Care 1-19 hours/week	8,097	5.3	298	3.7	1.10	0.98, 1.24	1.20	1.07, 1.36	1.34	1.17, 1.53
Care ≥20 hours/week	3,901	2.6	229	4.5	1.84	1.61, 2.12	1.33	1.15, 1.53	1.37	1.17, 1.61

No.: number of people; %: percentages; OR: odds ratios from logistic regression models; CI: confidence intervals

a: adjusted for age, sex and marital status

b: Model 1 + SES + area of residence

c: Model 2 + activity limitation+ mobility difficulties

Table 4.

Number of Deaths, Standardized Death Rates, and Hazard Ratios for Mortality Associated With Caregiving Status.

Caregiving status & Caregiver Age	Study Participants		Deaths		Standardised death rate ^d		Model 1 ^{a,e}		Model 2 ^{b,e}		Model 3 ^{c,e}	
	No.	%	No.	%	OR	95CI	OR	95CI	OR	95CI	OR	95CI
Aged 5-24												
Non-caregiver	413,269	95.5	438	0.1	25.0	22.5, 27.5	1.00	Referent	1.00	Referent	1.00	Referent
Caregiver	19,582	4.5	39	0.2	31.6	20.8, 42.4	1.40	1.01, 1.95	1.39	1.00, 1.93	1.54	1.10, 2.14
Aged 5-24												
Non-caregiver	413,269	95.5	438	0.1	25.0	22.5, 27.5	1.00	Referent	1.00	Referent	1.00	Referent
Care 1-19 hours/week	14,173	3.3	20	0.1	22.6	12.2, 33.1	1.05	0.67, 1.64	1.06	0.67, 1.65	1.21	0.70, 1.89
Care ≥20 hours/week	5,409	1.3	19	0.4	61.2	27.3, 95.1	2.19	1.37, 3.47	2.09	1.31, 3.33	2.16	1.36, 3.43

No.: number of people; %: percentages; OR: odds ratios from logistic regression models; CI: confidence intervals

a: adjusted for demography

b: Model 1 + SES + area of residence

c: Model 2 + activity limitation+ mobility difficulties and mental health

d. Standardised death rate per 100,000 of the population, standardised to the European Standard Population, 2013

e. Death rates per 100,000 of the population; Hazard Ratios estimated using Cox Proportional Hazards Models

Figure 1.

Odds Ratios for Reporting Mobility Difficulties According to Caregiving Input, Stratified by Age-group at the Time of the 2011 Northern Ireland Census (A: 5-17years, B: 18-24years, C: 25-44years, D: 45-64years, E: ≥ 65 years). Odds Ratios and 95% Confidence Intervals were estimated with Logistic Regression Models Adjusting for Demographic, Socio-economic and Area Factors.

Figure 2.

Odds Ratios for Reporting Poor Mental Health According to Caregiving Input, Stratified by Age-group at the Time of the 2011 Northern Ireland Census (A: 5-17years, B: 18-24years, C: 25-44years, D: 45-64years, E: ≥ 65 years). Odds Ratios and 95% Confidence Intervals were estimated with Logistic Regression Models Adjusting for Demographic, Socio-economic and Area Factors, plus Activity Limitation.

Figure 3.

Hazard Ratios for Mortality According to Caregiving Input, Stratified by Age-group at the Time of the 2011 Northern Ireland Census (A: 5-24years, B: 25-44years, C: 45-64years, D: ≥ 65 years). Results were Estimated Using Cox Proportional Hazards Models Adjusted for Demographic, Socio-economic and Area Factors, Activity Limitation and Mental Health.





